NICE National Institute for Health and Care Excellence

NICE Pathways

Managing symptoms for an adult in the last days of life

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/end-of-life-care-for-people-with-life-limiting-conditions
NICE Pathway last updated: 15 October 2019

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.

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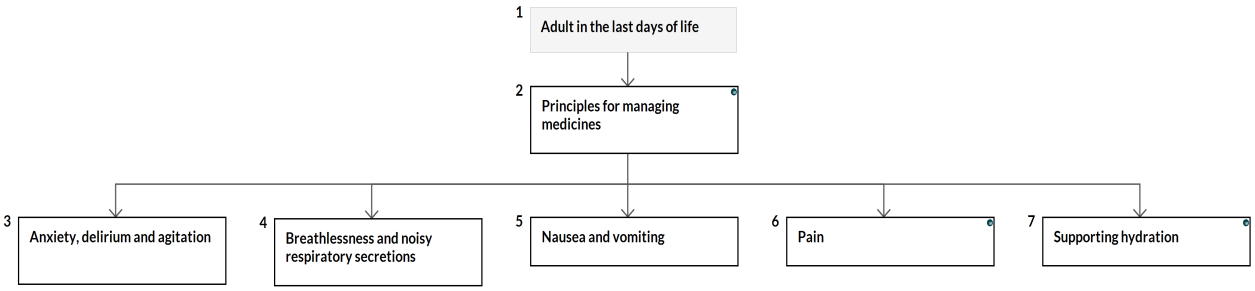

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1 Adult in the last days of life

No additional information

2 Principles for managing medicines

Providing appropriate non-pharmacological methods of symptom management is an important part of high-quality care at the end of life, for example, re-positioning to manage pain or using fans to minimise the impact of breathlessness, but this has not been addressed in these recommendations. This section focuses on the pharmacological management of common symptoms at the end of life and includes general recommendations for non-specialists prescribing medicines to manage these symptoms.

When it is recognised that a person may be entering the last days of life, review their current medicines and, after discussion and agreement with the dying person and those important to them (as appropriate), stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm.

When involving the dying person and those important to them in making decisions about symptom control in the last days of life:

- Use the dying person's individualised care plan to help decide which medicines are clinically appropriate.
- Discuss the benefits and harms of any medicines offered.

When considering medicines for symptom control, take into account:

- the likely cause of the symptom
- the dying person's preferences alongside the benefits and harms of the medicine
- any individual or cultural views that might affect their choice
- any other medicines being taken to manage symptoms
- any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.

Decide on the most effective route for administering medicines in the last days of life tailored to the dying person's condition, their ability to swallow safely and their preferences.

Consider prescribing different routes of administering medicine if the dying person is unable to

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take or tolerate oral medicines. Avoid giving intramuscular injections and give either subcutaneous or intravenous injections.

Consider using a syringe pump to deliver medicines for continuous symptom control if more than 2 or 3 doses of any 'as required' medicines have been given within 24 hours.

For people starting treatment who have not previously been given medicines for symptom management, start with the lowest effective dose and titrate as clinically indicated.

Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.

Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.

See also NICE's recommendations on medicines optimisation.

Anticipatory prescribing

Use an individualised approach to prescribing anticipatory medicines for people who are likely to need symptom control in the last days of life. Specify the indications for use and the dosage of any medicines prescribed.

Assess what medicines the person might need to manage symptoms likely to occur during their last days of life (such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain). Discuss any prescribing needs with the dying person, those important to them and the multiprofessional team.

Ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the dying person's needs change.

When deciding which anticipatory medicines to offer take into account:

- the likelihood of specific symptoms occurring
- the benefits and harms of prescribing or administering medicines
- the benefits and harms of not prescribing or administering medicines
- the possible risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) for which urgent symptom control may be needed
- the place of care and the time it would take to obtain medicines.

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Before anticipatory medicines are administered, review the dying person's individual symptoms and adjust the individualised care plan and prescriptions as necessary.

If anticipatory medicines are administered:

- Monitor for benefits and any side effects at least daily, and give feedback to the lead healthcare professional.
- Adjust the individualised care plan and prescription as necessary.

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Care of dying adults in the last days of life

3. Anticipatory prescribing

End of life care for adults

10. Specialist palliative care

3 Anxiety, delirium and agitation

Explore the possible causes of anxiety or delirium, with or without agitation, with the dying person and those important to them. Be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs for example, unrelieved pain or a full bladder or rectum.

Consider non-pharmacological management of agitation, anxiety and delirium in a person in the last days of life.

Treat any reversible causes of agitation, anxiety or delirium, for example, psychological causes or certain metabolic disorders (for example renal failure or hyponatraemia).

Consider a trial of a benzodiazepine to manage anxiety or agitation.

Consider a trial of an antipsychotic medicine to manage delirium or agitation.

Seek specialist advice if the diagnosis of agitation or delirium is uncertain, if the agitation or delirium does not respond to antipsychotic treatment or if treatment causes unwanted sedation.

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4 Breathlessness and noisy respiratory secretions

Breathlessness

Identify and treat reversible causes of breathlessness in the dying person, for example pulmonary oedema or pleural effusion.

Consider non-pharmacological management of breathlessness in a person in the last days of life. Do not routinely start oxygen to manage breathlessness. Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia.

Consider managing breathlessness with:

- an opioid[1] **or**
- a benzodiazepine **or**
- a combination of an opioid and benzodiazepine.

Noisy respiratory secretions

Assess for the likely causes of noisy respiratory secretions in people in the last days of life. Establish whether the noise has an impact on the dying person or those important to them. Reassure them that, although the noise can be distressing, it is unlikely to cause discomfort. Be prepared to talk about any fears or concerns they may have.

Consider non-pharmacological measures to manage noisy respiratory or pharyngeal secretions, to reduce any distress in people at the end of life.

Consider a trial of medicine to treat noisy respiratory secretions if they are causing distress to the dying person. Tailor treatment to the dying person's individual needs or circumstances, using 1 of the following drugs:

- atropine **or**
- glycopyrronium bromide **or**
- hyoscine butylbromide **or**
- hyoscine hydrobromide.

When giving medicine for noisy respiratory secretions:

- Monitor for improvements, preferably every 4 hours, but at least every 12 hours.
- Monitor regularly for side effects, particularly delirium, agitation or excessive sedation when

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[1] At the time of publication (December 2015), this medication did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

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- using atropine or hyoscine hydrobromide.
- Treat side effects, such as dry mouth, delirium or sedation (see recommendations in supporting hydration [See page 9], principles for managing medicines [See page 3] and anxiety, delirium and agitation [See page 5]).

Consider changing or stopping medicines if noisy respiratory secretions continue and are still causing distress after 12 hours (medicines may take up to 12 hours to become effective).

Consider changing or stopping medicines if unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation and unwanted levels of sedation, persist.

5 Nausea and vomiting

Assess for likely causes of nausea or vomiting in the dying person. These may include:

- certain medicines that can cause or contribute to nausea and vomiting
- recent chemotherapy or radiotherapy
- psychological causes
- biochemical causes, for example hypercalcaemia
- raised intracranial pressure
- gastrointestinal motility disorder
- ileus or bowel obstruction.

Discuss the options for treating nausea and vomiting with the dying person and those important to them.

Consider non-pharmacological methods for treating nausea and vomiting in a person in the last days of life.

When choosing medicines to manage nausea or vomiting in a person in the last days of life, take into account:

- the likely cause and if it is reversible
- the side effects, including sedative effects, of the medicine
- other symptoms the person has
- the desired balancing of effects when managing other symptoms
- compatibility and drug interactions with other medicines the person is taking.

For people in the last days of life with obstructive bowel disorders who have nausea or vomiting,

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consider:

- hyoscine butylbromide[1] as the first-line pharmacological treatment
- octreotide if the symptoms do not improve within 24 hours of starting treatment with hyoscine butylbromide.

6 Pain

Consider non-pharmacological management of pain in a person in the last days of life.

Be aware that not all people in the last days of life experience pain. If pain is identified, manage it promptly and effectively, and treat any reversible causes of pain, such as urinary retention.

Assess the dying person's level of pain and assess for all possible causes when making prescribing decisions for managing pain.

Follow the principles of pain management used at other times when caring for people in the last days of life, for example, matching the medicine to the severity of pain and, when possible, using the dying person's preferences for how it is given.

For a person who is unable to effectively explain that they are in pain, for example someone with dementia or learning disabilities, use a validated behavioural pain assessment to inform their pain management.

See what NICE says on opioids for pain relief in palliative care.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

End of life care for adults

10. Specialist palliative care

7 Supporting hydration

Support the dying person to drink if they wish to and are able to. Check for any difficulties, such as swallowing problems or risk of aspiration. Discuss the risks and benefits of continuing to drink, with the dying person, and those involved in the dying person's care.

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[1] At the time of publication (December 2015), this medications did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

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Offer frequent care of the mouth and lips to the dying person, and include the management of dry mouth in their care plan, if needed. Offer the person the following, as needed:

- help with cleaning their teeth or dentures, if they would like
- frequent sips of fluid.

Encourage people important to the dying person to help with mouth and lip care or giving drinks, if they wish to. Provide any necessary aids and give them advice on giving drinks safely.

Assess, preferably daily, the dying person's hydration status, and review the possible need for starting clinically assisted hydration, respecting the person's wishes and preferences.

Discuss the risks and benefits of clinically assisted hydration with the dying person and those important to them. Advise them that, for someone who is in the last days of life:

- clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may cause other problems (see below)
- it is uncertain if giving clinically assisted hydration will prolong life or extend the dying process
- it is uncertain if not giving clinically assisted hydration will hasten death.

Ensure that any concerns raised by the dying person or those important to them are addressed before starting clinically assisted hydration.

When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:

- whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment
- their level of consciousness
- any swallowing difficulties
- their level of thirst
- the risk of pulmonary oedema
- whether even temporary recovery is possible.

Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration is inadequate.

For people being started on clinically assisted hydration:

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- Monitor at least every 12 hours for changes in the symptoms or signs of dehydration, and for any evidence of benefit or harm.
- Continue with clinically assisted hydration if there are signs of clinical benefit.
- Reduce or stop clinically assisted hydration if there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want it.

For people already dependent on clinically assisted hydration (enteral or parenteral) before the last days of life:

- Review the risks and benefits of continuing clinically assisted hydration with the person and those important to them.
- Consider whether to continue, reduce or stop clinically assisted hydration as the person nears death.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

Care of dying adults in the last days of life

4. Hydration

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Advance Care Plan

(a formal care plan that includes details about the child or young person's condition, decisions made with them and their parents or carers [for example about managing symptoms], and their wishes and ambitions; this plan is a core element of their palliative care)

Carers

(someone who helps another person, usually a relative, partner or friend, in their day-to-day life [this term does not refer to someone who provides care professionally or through a voluntary organisation])

Holistic needs assessment

(considers all aspects of a person's wellbeing, their spiritual and health and social care needs; undertaking a holistic needs assessment ensures that the person's concerns and problems are identified so that support can be provided to address them [there are validated tools that can be used to support the assessment process])

Approaching the end of life

(the phase of illness after a change in the person's condition that means they are likely to die within weeks)

Approach the end of life

(the phase of illness after a change in the person's condition that means they are likely to die within weeks)

Holistic needs assessments

(consider all aspects of a person's wellbeing, their spiritual and health and social care needs; undertaking holistic needs assessments ensure that the person's concerns and problems are identified so that support can be provided to address them [there are validated tools that can be used to support the assessment process])

Chaplain

(an expert [with any or no religious beliefs] in religious, spiritual and or pastoral care for patients,

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families and staff, a chaplain also provides education and advice to organisations or trusts; chaplains work to a nationally recognised code of conduct and a set of standards and competencies)

Lead healthcare professional

(a member of the multidisciplinary team who assumes overall clinical responsibility for the delivery of care to a patient; they usually are a senior doctor or senior nurse)

Chaplains

(experts [with any or no religious beliefs] in religious, spiritual and or pastoral care for patients, families and staff, chaplains also provide education and advice to organisations or trusts; they work to a nationally recognised code of conduct and a set of standards and competencies)

Lead healthcare professionals

(members of the multidisciplinary team who assume overall clinical responsibility for the delivery of care to a patient; they usually are senior doctors or senior nurses)

Children

(aged 0–12 years, this includes neonates and infants)

Multipractitioner teams

(a group of practitioners from different clinical professions, disciplines, organisations and agencies who together make decisions on the recommended treatment for individual patients)

Child

(aged 0–12 years, this includes neonates and infants)

Dying

(when the child or young person is likely to die in hours or days)

People managing and delivering services

(commissioners, planners and service providers responsible for overseeing local health and

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social care provision and accountable for public service outcomes)

End of life care

(in this interactive flowchart, end of life care for a child or young person includes the care and support given in the final days, weeks and months of life, and the planning and preparation for this)

Service providers

(all organisations [including primary, secondary, tertiary, ambulance and hospice services] that provide NHS services for people approaching the end of their life)

Life-limiting condition

(a condition that is expected to result in an early death, either for everyone with the condition or for a specific person)

Life-limiting conditions

(conditions that are expected to result in an early death, either for everyone with the condition or for a specific person)

Young carer

(someone aged under 18 who helps another person, usually a relative, partner or friend, in their day-to-day life [this term does not refer to someone who provides care professionally or through a voluntary organisation])

Neonates

(babies aged up to 28 days)

Neonate

(baby aged up to 28 days)

Paediatric palliative care

(an approach to care covering physical, emotional, social and spiritual support, which focuses

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on improving the quality of life for the child or young person and supporting their family members or carers, and includes managing distressing symptoms, providing respite care, and support with death and bereavement)

parallel planning

(planning for end of life care while taking account of the often unpredictable course of life limiting conditions; it involves making multiple plans for care, and using the one that best fits the child or young person's circumstances at the time)

Young people

(aged 13–17 years)

Young person

(aged 13–17 years)

Sources

Care of dying adults in the last days of life (2015) NICE guideline NG31

Your responsibility

Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They

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should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the

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interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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